

# **COMMENT ON THE UTILITY OF THE ADDGS EVALUATION FOR POLICY AND PRACTICE**

Melanie K. Starns, M.A.G.

Administration on Aging, U.S. Department of Health and Human Services

Address correspondence to Melanie K. Starns, Administration on Aging, Washington, DC 20201;

e-mail: [Melanie.Starns@aoa.gov](mailto:Melanie.Starns@aoa.gov)

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### ABSTRACT

This article comments on the policy and practice implications of findings from research on the Administration on Aging's Alzheimer's Disease Demonstration Grants to States Program. Evaluation of fifteen state grantees has produced extensive knowledge about diverse patterns of service use, factors related to service use and satisfaction, mechanisms for developing home- and community-based services appropriate for various cultural groups, and ways to adapt established programs and integrate new services into existing systems and networks. Utilizing the general lessons from the Alzheimer's Demonstration Program evaluation in program and policy development in aging is discussed.

**Keywords:** Alzheimer's disease – Minorities – Service Delivery – Caregivers – Aging – Dementia – Rural – Program Development

## COMMENT ON THE UTILITY OF THE ADDGS EVALUATION FOR POLICY AND PRACTICE

The collection of articles in this issue provides extensive data that underscore the variety of ways that the Administration on Aging's (AoA) Alzheimer's Disease Demonstration Grants to States (ADDGS) program can be seen as a success. At the most basic level, the demonstration projects funded through the program have successfully reached underserved populations. As noted in the initial article by Montgomery et al., the delivery of over 3,500,000 units of service to over 14,400 families is especially impressive because 90% of the clients were either members of underserved minority groups or resided in rural areas.

Equally important, however, are the insights gained from the demonstration projects that will inevitably benefit future programs and clients. Specifically, the set of articles in this issue highlight the extensive knowledge that has been gained about diverse patterns of service use, factors related to service use and satisfaction, mechanisms for developing home and community based services appropriate for various cultural groups and ways to adapt established programs and integrate new services into existing systems and networks.

Although each of the five articles offer many insights and lessons for replication, when considered together three general lessons emerge as particularly valuable. The first lesson concerns the importance of recognizing and learning about cultural differences. Both the quantitative data pertaining to clients' attitudes and beliefs about caregiving and the qualitative data gathered through formal and informal interviews with staff underscore significant differences associated with culture. Yet, while these differences have apparent implications for outreach activities and designing user-friendly services, they are less important with respect to client satisfaction. To effectively reach and serve underserved populations it is important to build awareness of client needs and services within the target communities and establish a sense of trust and credibility with community leaders and prospective clients. Findings from the evaluation remind us that this strategy is grounded in a respect for both the differences and unique knowledge that exist within different cultures and within different organizations.

To successfully serve underserved groups many of the demonstration's sites discovered that it was important to educate client populations about Alzheimer's disease and resources and to simultaneously teach staff members of provider organizations about cultural preferences and experiences. Several of the demonstrations were very effective in their efforts to serve their targeted populations because they built strong community commitment through partnerships with established community organizations and agencies that had credibility within the community. El Portal, the program developed to reach Latinos in Los Angeles, serves as an excellent exemplar of a program that successfully used this model of development. For this project to succeed, trust had to be built among the partner agencies, and mechanisms had to be found for these agencies to work together. All partners had to be honest about the resources they could bring to the project. It was essential that organizations not promise services or resources they could not deliver. Initial service efforts focused on educating local professionals and providers about dementia issues. Yet, the project initially overlooked the importance of working within cultural norms and expectations. Thus, during the first year of the project, materials were translated into Spanish, professional staff were educated, and resources were distributed throughout the Latino community. However, few families responded. What the project had missed was critical – the materials and services were developed to meet the traditional understanding of what families facing Alzheimer's disease needed, but lacked cultural relevance for the Latino community. During subsequent years, the El Portal project worked closely with community partners to develop information and services that addressed Alzheimer's disease in the social, religious, and cultural context of the Latino family and of the Latino community in which the program operated.

A similar finding resulted from the SeaMar project in Seattle, Washington. This project clearly demonstrated the importance of working from within the community being served and addressing the cultural context of information and service delivery, even if the services being offered are outside of that community. Through their care advocate model, the Washington project identified the same important issues as did the El Portal project: that staff as well as the community require education, that establishing community trust and credibility are key, and that community partnerships are essential to long-term viability of the program.

A second general lesson gained from the demonstration concerns the importance of generating new resources to foster the longevity of new programs. Although demonstration resources were valuable for creating many of the new programs, it was the new partnerships that reinforced state and local commitment that led to the creation of new legislation and financial resources to support the programs beyond the demonstration period. The flexibility of the demonstration fostered a variety of mechanisms among the various grantees. While some states, like Maine and Ohio, used the advocacy forces that resulted from the demonstration to generate long-term state funding, other grantees, like South Carolina and California successfully leveraged demonstration funds to obtain new and continued funds from private sources. For instance, in California, the partnerships resulting from El Portal not only created a guiding body for the project, but also formed a network of public and private entities interested in the long-term survivability of the project. Because so many of the partners were located within the Latino community in which El Portal operated, their interest and commitment was stronger than if the partners had been external to that community.

As both the articles by Montgomery et al., and Karner et al., note, new resources also emerged in the form of technical assistance that was provided by the states to local areas. For example, the state grantee in Oregon created a comprehensive training program on dementia for case managers, and offered the training to case managers involved with the demonstration grant as well as to those who were not. The training is an example of how the demonstration project was able to leverage resources and provide a scope of technical assistance far broader than the project itself. In North Carolina, one of the key partners in the demonstration project was Duke University. Through the combined technical resources of the state and the university, the successes from the demonstration project were replicated across the state, expanding beyond the scope of the original demonstration project. To further the provision of technical assistance nationally, replicable aspects of successful demonstration projects have been identified and key characteristics for success discussed in brochures made available on the Administration on Aging's Alzheimer's Resource Room website at <http://www.aoa.gov/alz>. Specific information on successful service delivery strategies may be found at [http://www.aoa.gov/alz/profprov/pp\\_s\\_strategies.asp](http://www.aoa.gov/alz/profprov/pp_s_strategies.asp).

Finally, a third general lesson gained from the ADDGS program pertains to the value of flexibility in both the administration and design of programs. A hallmark of the demonstration program has been the commitment to a level of flexibility that affords opportunities for communities to adapt existing services to meet emerging needs and to create new services and delivery models that augment established systems. In this way, communities were able to foster a continuum of support services for families. The wide variation in programs documented by the initial article in this volume speaks to the success of this strategy.

This creativity is exemplified by the mobile day care programs created in Georgia and the rural assessments teams assembled in Maine. For instance, Georgia created an entirely new model of adult day care that addressed low population densities, workforce shortages, and urban and rural differences. Mobile day care is an innovative approach to providing social day care in communities that may not have the resources to develop their own full-time, day care program. Leaving each morning from a central location, program staff (with materials and supplies needed for the day) travel to the adult day care site. Depending on the needs of the community, each center is open one or two days per week, for six hours a day. Day care is held in a community building (church, senior center, etc.) in the community. When possible, transportation for participants is arranged through community resources. While the Georgia model was specifically developed to address adult day care needs of communities in rural Georgia, the model itself can be adapted for use in more urban areas, where neighborhoods may have a need for adult day care but cannot support a full-time facility.

The Maine demonstration project created five evaluation teams to serve four isolated counties in rural, northeastern Maine. Each team consisted of a Social Worker and a Registered Nurse. The teams provided the only dementia evaluation service in these remote areas. The evaluation includes two home visits by the team, consultation with a geriatric physician, the development of an individualized care plan, and two telephone follow-ups. Designed to address the considerable difficulties of transportation, weather, and culture that results in a lack of appropriate diagnosis and care of persons with Alzheimer's disease, this model is quite successful. Both the programs in Georgia and Maine illustrate the benefits of the flexibility the demonstration afforded states

and communities to develop specific strategies and approaches that address the unique needs, interests, resources, and culture of each project site.

Equally important to the value of this demonstration for future efforts is the flexibility that has been extended to the evaluation process. Over the duration of this demonstration, the focus of the evaluation has moved from basic documentation of service delivery and delivery models to extensive analysis of client patterns of service use. These analyses will draw the attention of future providers, not only to the diversity of caregivers, but also to elements of the service delivery that clearly impact service use such as hours of operation, fee structures, staff training and staffing patterns.

Many of the lessons gained from the ADDGS program have already been used by new demonstration grantees. In November 2000, successful “first generation” ADDGS grantees were brought together with new ADDGS grantees at a national meeting in Washington, DC. Serving as mentors to the new grantees, the “first generation” grantees shared their experiences – successes as well as pitfalls – in an effort to assist new grantees to build on the knowledge gained through the first set of demonstration projects. For instance, staff from the El Portal project shared their first year pitfall of creating services and materials but failing to educate and build partnerships within the Latino community, and explained how they overcame such obstacles. This information was key to new grantees planning to work with Hispanic and Latino communities, as well as those working with other cultural groups.

Staff from Georgia’s mobile day care and the District of Columbia’s Al-Care program also participated in the meeting. Al-Care was a demonstration program that focused on serving persons with Alzheimer’s disease who lived alone and had few informal supports. Through presentations and informal, but detailed, discussions with previous grantees, the new grantees were able to glean specific ideas for service delivery models, as well as identify potential pitfalls. Likewise, new grantees were also able to develop a better understanding of the steps necessary to ensure long-term viability and funding of project services. Perhaps the most significant lesson that all veteran grantees shared, however, is the importance of taking time to build solid

partnerships and trust within the target community. Without these two elements, projects were generally not successful.

The new grantees have also benefited from the evaluation as they have learned that one size does not fit all caregivers, nor does one size fit all communities. The new grantees are well aware that with adequate resources and support for development most communities are able to develop supports systems that will continue beyond the demonstration period.

The findings reported in this series of articles are not only useful for other communities that wish to implement support services for Alzheimer's families, but are also useful for tailoring the development and implementation of support programs for various service populations to the needs of local communities. Indeed, the findings of the Alzheimer's Demonstration Program are already being used in some states to guide practice and policy development related to AoA's new National Family Caregiver Support Program (NFCSP) established December 2000. For instance, in Washington, results of their ADDGS project and data from the ADDGS program were used in conjunction with information about family caregivers to develop state legislation related to family caregivers. And in several states across the country, the ADDGS program and the NFCSP are being carefully integrated to ensure that caregiver services are incorporated as part of the broader home and community based care system and do not develop as separate parallel service structures.

While the population being served under the NFCSP is broader than it is in the ADDGS program, *flexibility* and *partnerships among public and private organizations* are critical aspects built into both programs. Additionally, the NFCSP was created with the recognition that there is great diversity among caregivers in their responsibilities, activities and their needs for support, just as there is great diversity among the communities and states in which family caregivers reside. This recognition has led to the implementation of a caregiver program that is promoting innovation, creativity, and the development of a continuum of services that to meet the needs of family caregivers as they change throughout the caregiving process.



Thus, as new models of service delivery and community based care continue to be developed under the ADDGS program, we will continue to learn more about how to work effectively with various populations and communities, and how to be successful working within the social and cultural context of those communities. With the widespread dissemination of ADDGS program results, we hope to further the knowledge and understanding of successful approaches to developing service delivery strategies for persons with Alzheimer's disease. And with time, these lessons will permeate the program and policy development of aging services, thereby enhancing our capacity and effectiveness in reaching all families facing the challenges of aging, regardless of their culture, ethnicity, income, or geographic location.

For more information about the Administration on Aging's Alzheimer's Disease Demonstration Grants to States program, please visit our website at <http://www.aoa.gov/alz>. The Administration on Aging is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers through a national aging network of state and local agencies on aging, tribal organizations, service providers and volunteers.